



17th Year Anniversary Booklet

THE
DONOR SIBLING REGISTRY



EDUCATING, CONNECTING AND
SUPPORTING DONOR FAMILIES

Educate, Connect and Support

Educate: Prospective parents, parents, egg/sperm donors, offspring, the infertility industry, and the public:

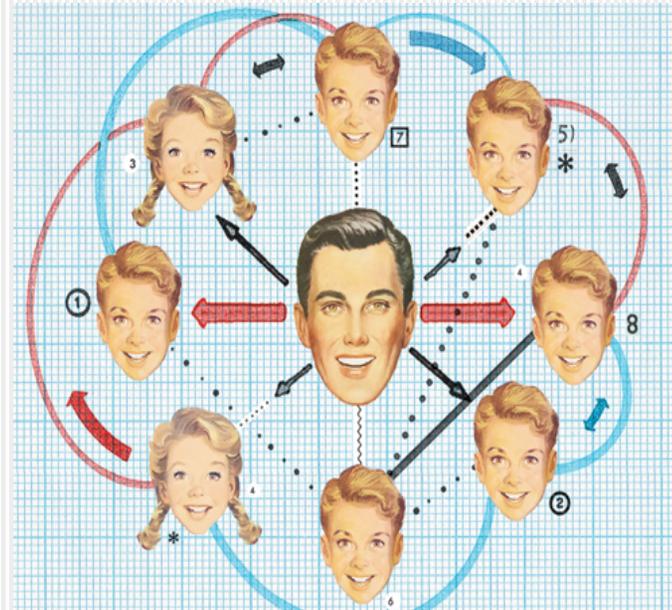
- Our website
- Research/published papers
- Articles, blogs, and commentaries
- Speaking at conferences, organizations, universities
- Media stories: print, TV news, documentaries, book, and 2 DSR TV shows produced (1 Emmy nomination)
- Outreach programs: SMC, LGBTQ, infertility, bioethics, medical, legal, psycho-social, academic, repro. medicine

Connect and Support:

- Facilitate connections among donor families
- Licensed therapists available
- Online group forum for advice, discussion and support
- Families now have a community

DSR membership: 55,000 in 105 countries

DSR matches: 15,000 matched (half sibling and/or donor-offspring connections)



Recipients and Donors: Education and Counseling



62%

... of sperm donor recipients had no pre-insemination counseling.

49%

... saying, "it never occurred to me".

72%

... of husbands/partners never received counseling.

80%

... of sperm donors say they were not counseled on offspring's curiosities.

66%

... of egg donors felt that they were not properly educated and counseled on offspring's curiosities.



Parent Membership

50% Single Mothers by Choice | 33% LGBTQ | 18% Heterosexual Couples

"My partner and I have two beautiful daughters from a donor. While we are very content with our family, we have always wanted our daughters to have the option of exploring their biological siblings/donor; plus we are so curious about traits, behaviors, and medical issues of other half-siblings out there.

This is a wonderful service that brings together a community of people that often feel stigmatized or outside of 'mainstream' America. Individuals can control their privacy and can pursue whatever level of involvement they choose, and do so comfortably."



Janice Grimm & Sharon Josefson
(together 26 years, married 2 years)
with their 16 yr. old twins Sara & Jordan,
and Sunny, their rescued pitbull mix.

“With your help we’ve connected with two of our kid’s half sibs. Thank you for all that you’ve done and continue to do!”

**DONOR SIBLING
REGISTRY®**

www.DonorSiblingRegistry.com

1/3 of the DSR’s 52,000 members are in LGBTQ families.



**Embracing
Family**

(join today)

- 1/3 of our nearly 50,000 members are in LGBTQ families
- Help your children build their extended half-sibling family
- Share photos and medical info
- Network with other families

“In my family...we are committed to not only doing our best for her as an infant, a child, an adolescent, and a teenager... but also looking out for her best interests as an adult.”

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REGISTRY®**

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SUPPORTING DONOR FAMILIES

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Anonymity: We need to be asking, “what is in the best interests of the children to be born?”

The US must consider banning anonymous donations. The HFEA UK numbers of new donors registered show donors increasing since banning anonymous donations in 2005.

YEAR	SPERM DONORS	EGG DONORS	YEAR	SPERM DONORS	EGG DONORS
1992	375	451	2003	257	1,032
1993	426	528	2004	239	1,107
1994	417	732	2005	272	1,023
1995	414	749	2006	303	803
1996	419	806	2007	360	803
1997	343	910	2008	405	1,167
1998	256	943	2009	438	1,258
1999	302	1,120	2010	480	1,258
2000	323	1,241	2011	541	
2001	327	1,302	2012	631	
2002	288	1,174	2013	586	

2005
Identity disclosure went into effect.

Other countries that have banned anonymous donation: Norway, New Zealand, The Netherlands, Sweden, Austria, Switzerland, Finland, Australia (Western Australia and Victoria), Germany and Ireland.

Anonymity carries potential medical risks to offspring when they are ignorant of the evolving medical history of their unknown biological relatives.

DNA = Donors Not Anonymous

Due to the advent of commercial DNA testing, donor anonymity no longer exists and should not be promised by any sperm bank or egg clinic.

“Many thousands of people worldwide have been conceived with donor gametes but not all parents tell their children of their origin. Genetic testing will make this impossible. Over three million people have already used direct-to-consumer genetic testing. The rapidly increasing availability of cheaper and more detailed tests poses numerous challenges to the current practice of sperm and egg donation: 1. Whether they are donating in a country that practices anonymous donation or not, donors should be informed that their anonymity is no longer guaranteed, as they may be traced if their DNA, or that of a relative, is added to a database. 2. Donor-conceived adults who have not been informed of their status may find out that they are donor-conceived. 3. Parents using donor conception need to be fully informed that their children’s DNA will identify that they are not the biological parents and they should be encouraged to disclose the use of donor gametes to their children.

All parties concerned must be aware that, in 2016*, donor anonymity has ceased to exist.”

-JLH (Hans) Evers, Editor-in-Chief Human Reproduction, 2016

*Donor anonymity ceased to exist when the first donor offspring located his donor via DNA testing in 2005.

Reference: New Scientist Magazine 11/3/2005



Advice: Parents and Offspring

If you chose (were given) an anonymous donor, do you now wish that you had used an open/identity release/willing to be known donor?

More than 60% ... of 1700 surveyed sperm donor recipients answered “yes”.*

More than 49% ... of 108 surveyed egg donor parents answered “yes”.*

More than 70% ... of surveyed donor offspring recommend that parents use an open or willing-to-be-known donor.

*The majority of these parents still had very young children.



Redefining Family: How do we define family?

Terminology: More than half of 751 surveyed donor conceived people used the words “father” or “dad” to describe their donor.

Only 22% of sperm donor recipients used those words when describing the donor, sometimes saying it was “just a donated cell” or “just a piece of genetic material”.

83% ... of offspring who are not in contact with their donors, wish to be.



Blended family: Egg donor and her 2 daughters meeting her 16 year old egg donor-daughter, with her parents on the Katie Couric Show



Ryan Kramer and his three half-sisters

Acknowledgement: The importance of searching and connecting

From a parent:

“This is just the first day and already we located 5 half-siblings to my son, and communicated by email and by phone with one of them. This event is absolutely HUGE in the life of my son who has grown up in our little family of two all his life (plus assorted pets). He's always longed for brothers and sisters and now it has happened for him. My heart is so full for him.

At the age of 12 and newly embarking on the enormous task of figuring how who he is in this world, this is a life-changing event for him. It's just beginning to sink in just how big... What a great day.”

For this 18 year-old donor conceived person it is much more than a “donated cell”. Her donor’s number is now tattooed on her left foot.



Half Siblings: Contact



"Our kids are two and half years old. They are only 3 weeks apart in age. They are so alike and they are so different. They spent 4 days together, fighting and playing and then fighting some more. Within our individual families they were only children. In our new family they are very much sister and brother. There aren't words to explain the sense of peace that has given us as parents. There's no yardstick that can measure how much this has enriched our lives."

Of those who had connected with half siblings:

32% ... describe the relationships like "brothers & sisters"

18% ... like "acquaintances"

12% ... like "good friends"

9% ... like "close relatives"

8% ... like "cousins"

"I just found my half-sibling this year. I am 29 years old and wish that I could have known him my whole life. It is really special, and I'm so thankful to have found him. We met a couple of months ago and it's like we have known each other all along."



Parents: Tracking and Limits



(This photo is not of the half sibling group of 200. It does show 200 people, so that we can see what 200 half siblings might look like as a group!)

"I was pretty overwhelmed when I was pregnant and found your site. There were 50 kids listed for my donor. It is probably getting closer to 200 now." – DSR Mom, April 2012

45% ... of sperm donor recipients had no request by the sperm bank or clinic to report the birth of their child(ren).

31% ... of those say that the sperm bank is unaware of the birth of their child.

42% ... of egg donor parents were never asked to report their births.

Limits:

43% ... wanted to see a maximum of ten offspring, 32% a maximum of ten families, per donor.

78% ... think that sperm donors should be restricted from donating at multiple banks.

Sperm Donors: Contact



Donor Todd meeting some of his donor children in 2007 and a few more in 2016. An ever-expanding family with half siblings meeting for the first time!



164 Surveyed Sperm Donors:

72% ... currently married - 85% of spouses were open to contact.

57% ... with children, 71% of donor's children (old enough) wished to have contact with half siblings.

94% ... were open to contact with offspring. Of those, 94% were willing to answer questions, 90% willing to share medical info, 89% willing to share photos, 88% willing to exchange emails, and 85% willing to meet.

Sperm Donors: Offspring Limits

35% of sperm donors were told there would be limits on the number of offspring produced- anywhere between 3-25 children were promised.

Many sperm donors are surprised (shocked) to learn of many more on the DSR. The bravest donor registered on the DSR has 75 donor children all under the age of 13.

The largest group is currently around 200.



"Married, no. Kids... well, I was a sperm donor... So I may have dozens! You?"

Sperm Donors: Experiences



“Read up on the current wisdom and knowledge that’s developed over the years. There’s more to it than making a few bucks.”

From a donor who connected with a 10 year old daughter 6 years ago:

“Finding K was certainly a life-changing experience. Becoming a father overnight to a ten-year-old was frankly terrifying. Usually parents get a few years of trial and error before the kid remembers anything. Becoming Katie's father was a growing experience for me, and I credit her with teaching me how to be a father.”

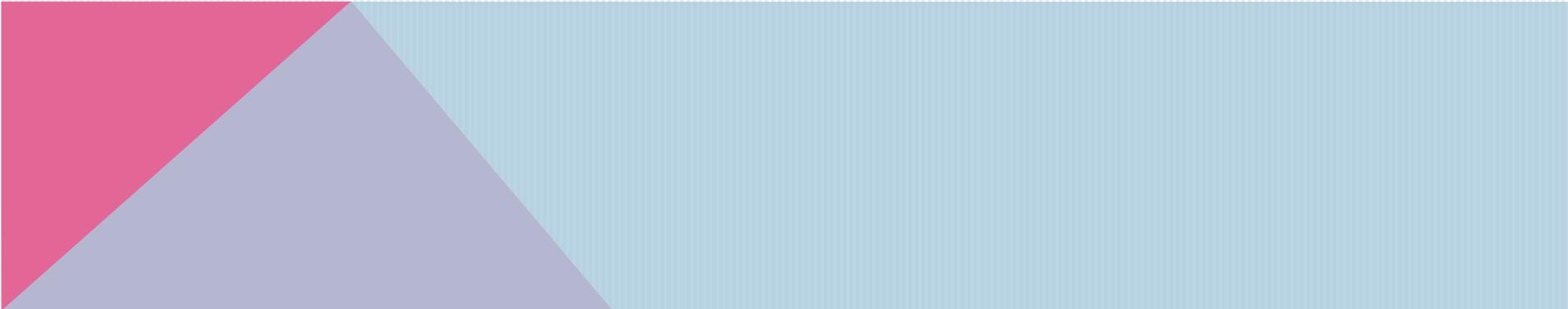
And from another donor:

“You are involved in the creation of real people, not an abstract concept. They will live and breathe and grow, and they will want to know about you. Be ready to have a big heart.”

Health: Egg and Sperm Donors

- 74%** ... of donor offspring who wish to make contact with their donors list learning more about their medical background as a reason for the desired contact.
- 84%** ... of 164 surveyed sperm donors have never been contacted by their clinic(s) for medical updates.
- 97%** ... of 155 surveyed egg donors have never been contacted by their clinic(s) for medical updates.
- 23%** ... of sperm donors felt that they or close family members had medical/genetic issues that would be important to share with families.
- 31%** ... of egg donors felt they or close family members had medical/genetic issues that would be important to share with families.
- 94%** ... of surveyed sperm donors would have accepted an offer for genetic testing, had it had been offered by their sperm banks.

Sperm donor recipients say that health information was the most important factor when choosing a donor:

- 78%** ... wish that all donors were psychologically tested.
 - 67%** ... believe that sperm banks should be legally required to comprehensively genetically test all donors.
 - 84%** ... said that they would be willing to pay more for sperm that had undergone comprehensive genetic testing.
- 

Current Testing Requirements & Medical Issues Reported

Current US* Screening:

Sexually Transmitted Diseases: HIV, HTLV, Hepatitis B & C, Syphilis, Gonorrhea, Chlamydia, CMV
Genetic testing varies significantly at US clinics as adhering to ASRM "recommendations" is voluntary.

The less screening carried out, the fewer donors need be disqualified. Fewer tests also equals less cost.
Some clinics and sperm banks test some donors for some of the following: Cystic Fibrosis, Sickle-Cell Disease, Tay Sachs, Canavan Disease, Gauchers Disease, Nieman-Pick's Disease, B-Thalassemia

Medical Issues and the Donor Conceived Person:

Medical and genetic issues reported by sperm and egg donors for themselves or their immediate family include:
Albinism, Alcoholism, Asperger's, Autism, Bi-Polar Disorder, Brain Aneurysm, Breast Cancer, CF Carrier, Canavan Disease, Cavernous Angioma, Colon Cancer, Congenital Heart Disease, Diabetes, Hashimoto's Syndrome, Hemochromatosis, High Blood Pressure Leading to Stroke, Leukemia, Lung Cancer, Melanoma, Mitral Valve Prolapse, Multiple Myeloma, Multiple Sclerosis, Polycystic Kidney Disease, Prostate Cancer, Rheumatoid Arthritis, Spinal Muscular Atrophy, Ulcerative Colitis

Some Privately Reported Health/Genetic Issues from Parents and Offspring: Acute Lymphoblastic Leukemia, ADD, ADHD, Albinism, Amniotic Band Syndrome, Asperger's, Asthma, Atrial Septal Defect, Auto Immune Thyroiditis, Bi-Polar Disease, Branched-chain Ketoaciduria, Complex Congenital Heart Defect, Congenital Heart Disease, Congenital Hypothyroidism, Cystic Fibrosis, Dwane Syndrome, Ebsteins Anolomy, Ectodermal Dysplasia, Heart Murmur, Hemoglobin D, Hemophagocytic Lymphohistiocytosis, Hole in Heart, Horseshoe Kidney, Hydrocephalus, Hypertrophic Cardiomyopathy, Hypophosphatasia, Hypospadias, Imperforated Anus, Juvenile Dermatomyositis, Juvenile Arthritis, Keratosis Pilaris, Kidney Disease, Lethal Dwarfing Syndrome, Marfan's Syndrome, Medium Chain Acyl CoA Dehydrogenase Deficiency (MCAD), Metabolic Genetic Disorder, Mitral Valve Stenosis, Multiple Hereditary Exostoses, PANDAS, PHACES Syndrome, Phenylketonuria (PKU), Polycystic Kidney Disease, Prader-Willi, Rasmussen's Encephalitis, Renal Disease, Retinoblastoma, Seizure Disorders, Severe Congenital Neutropenia, Spina Bifida, Spinal Muscular Atrophy, Tay Sachs, Tourette's, Tracheo-Esophageal Fistula, Truncus Arteriosis, Type I Diabetes, Van Der Woude Syndrome, Vesicoureteral Reflux, Von Willebrand Disease, Williams -Beuren Syndrome, Zellweger Syndrome

*This is not just a US problem as US Sperm banks claim to ship sperm to 50-60 countries around the world

How many donor offspring born per year? (No Current Tracking!)

In 1988 the Office of Technology Assessment estimated that 30,000 children were born via donor insemination during the year 1986/1987 in the US.

More than a quarter of a century - and no further research - later, '30,000 annual births' is still trotted out by "experts" in academia, lectures and through the media. Sometimes the number is doubled, so that occasionally a range of 30,000 - 60,000 is deployed. Using either of the whole figures is scientifically unjustifiable, and the range is just as flawed.

Experts should not be using such patently erroneous figures. Rather, they should be noting that there is no reliable method of assessing how many children are conceived via donor insemination each year. They should be pointing out that the USA has no accurate tracking or record keeping from which it is possible to make an educated assessment.

Instead of complacently relying on outdated best guesstimate figures from more than a generation ago, they should be demanding accurate record keeping and reliable, recent figures. They should be voicing outrage that neither the fertility industry nor any other entity is required to collect data or report statistics on the numbers of human beings conceived using donor eggs or sperm.

This is in stark contrast to artificial insemination within the cattle industry, which is much more tightly regulated and surveyed.

ASRM and SART Oppose Regulation

The American Society of Reproductive Medicine (ASRM) and the Society for Assisted Reproductive Technology (SART) continue to fight the ideas of donor registries, accurately tracking offspring births, banning anonymous donations, and limiting the number of children born from any one donor.

February 20 , 2012, ASRM Office of Public Affairs:

ASRM/SART sent a letter of opposition to members of the New York House and Senate health committees regarding problematic sperm donor legislation. AB 9039/SB 6272 would curtail the rights of patients who need a sperm donor to build their families.

The bills would limit to ten the number of offspring anyone donor can conceive and create a donor registry in the state. ASRM argued there is no scientific evidence to support the cap at ten and referenced existing professional guidelines while maintaining a single state based registry would not only be ineffective, but also intrusive.

The ASRM says it will strongly oppose any move to ban anonymous donations. "We think that people ought to be able to build their families the way they see fit," says Sean Tipton, a spokesperson for the ASRM. "And you don't change the rules in the middle of the game."

*"First you
have
a desire,
then
a need,
then
a right,
and then
finally,
a law."*

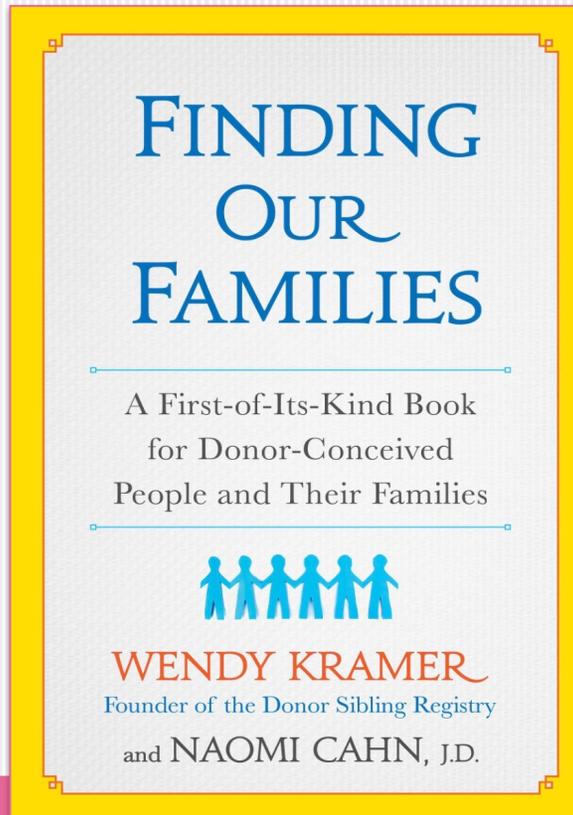
*- Governor
Jerry Brown*

What have we learned?

1. There is inadequate record keeping currently maintained by the infertility industry. 20, 50 and more than 200 kids from one donor can be harmful to families: random meetings, medical issues, and for psycho-social reasons. Many of these children will have little chance of ever meeting their donor, just because of the size of their group.
2. Recipients and donors are not adequately educated/counseled BEFORE donation and conception. This must be done to ultimately serve the best interests of the children being born. The initial decisions that parents make will greatly affect their children for decades to come.
3. The importance of parents-to-be having all pertinent information on prospective donors and the children they have already produced. Connecting can happen before insemination, during pregnancy, when children are young, or by adult donor conceived people. Many prospective parents are actually choosing their donors through the DSR- reaching out to the other families first to check on numbers of half siblings, medical issues, to share photos and to establish relationships.
4. The importance of early disclosure and a child's right to know the truth. Don't wait to tell!
5. The importance of honoring offspring curiosities and their right to search for, and to find their genetic relatives. Confident and secure parents are not threatened by these connections. Be a confident parent!
6. The importance of connecting: for donors, parents and for offspring. Also, for the extended families - wives, children and parents of donors.
7. The great majority of donor conceived people and their parents recommend that parents use open donors. Anonymity should be banned.
8. Donors should never be promised anonymity - it's an outdated and unrealistic promise considering DNA testing, social media, and Google.
9. There is currently no comprehensive medical and genetic testing of donors. *Some* clinics, test *some* donors, for *some* diseases. FDA regulations cover STD's and a small handful of other diseases. This affects families in the more than 60 countries where US and Danish sperm is shipped.
10. The importance of being able to update and share medical information among families, for all: parents-to be, parents, donors and offspring. *Clinics outside the US need to let recipients know where the sperm originated from!*
11. Some sperm banks refuse to give donors their donor numbers- this prohibits donors making mutual consent contact with recipient families and sharing medical information.
12. Some sperm banks allow their "open" or "willing-to-be-known" donors to change their minds and to refuse contact when a child turns 18.
13. There is little regulation and/or oversight. The infertility industry claims to "self-regulate" while halting all attempts to regulate. A multi-billion dollar industry with little to no oversight or regulation: ***what could possibly go wrong?***

Finding Our Families: The Book

The first comprehensive book for people born through donor conception and their families.



If you are thinking about having a baby through donor conception, this book is for you. If you are a donor conceived person, this book is for you. If you are a parent raising a child who came to you through the help of an egg or sperm donor, this book is for you. If you are a medical or mental health professional, helping people build their families through donor conception, this book is for you...

-Ellen Sarasohn Glazer LICSW, Co-Author, "Having Your Baby Through Egg Donation"



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